

Insights

How One Mom is Raising the Profile of Sickle Cell Disease

Tammy Smith's daughter, Precious, often got sick as a baby and she cried—a lot. "One time she was holding her arm and we thought it was broken, but it wasn't. Another time she couldn't even sit up. She would just cry and cry. The doctors kept giving us medicine, but it didn't help," recalls Tammy.

It wasn't until Precious became so sick and nearly died that Tammy took her to a different hospital for treatment and learned that Precious had sickle cell disease (SCD). The inherited blood cell disorder causes red blood cells to morph into a crescent ("sickle") shape and get stuck in small blood vessels. This blockage inhibits blood flow, which deprives tissues of oxygen and causes severe pain and tissue damage. Precious received her first blood transfusion at the age of two. It was the beginning of many stays in the hospital that would prove isolating and difficult for the young family.

"We spent a lot of time at the hospital and I just didn't talk about it with anyone. My family knew, but friends didn't," says Tammy. "When Precious got sick, it was usually in the middle of the night and we would go to the hospital. It felt like we were the only ones in the world going through it. I didn't know anyone else around me that had sickle cell disease. I didn't have the information that is available for people now."

Fast forward 30 years and Tammy is making sure other families don't have the same experience that she and her daughter had.

"I decided that something bigger had to be done in order to bring awareness to the community, assist families with financial support, and most importantly encourage more studies and research to be done to find a cure for sickle cell disease," says Tammy.

The motivated mother started a nonprofit in 2013 called [A Precious Organization for Sickle Cell](#). Its mission is to "provide moral support, counseling, community meetings, and financial assistance to alleviate some of the pressures that one may encounter while coping with the disease and to make a difference nationwide as an advocate for all who suffer from sickle cell anemia by being a voice and ambassador for a cure."

The Illinois-based organization hosts a support group once a month for sickle cell patients and their loved ones. It conducts an annual fundraising walk to assist individuals with medical bills and transportation to and from the hospital. In 2013, the organization raised \$10,000 with 400 participants. Last year it was \$12,500 and 500 participants. The organization has also petitioned politicians for policy development for improved treatments, medicines and research.

Tammy also became active in her local Sickle Cell Disease Association of America (SCDAA) chapter and became a parent partner in the [Working to Improve Sickle Cell Healthcare \(WISCH\) project](#), led by NICHQ. The WISCH project aims to improve screening and follow up for those who have tested positive for sickle cell disease and trait, and improve care across the lifespan for individuals with sickle cell disease.

Since she recently learned her three-year-old grandson has SCD, Tammy's desire to educate people about SCD and support those with the diagnosis has only intensified.

"I went from having not told anyone that my daughter had sickle cell to being known as the sickle cell lady," says Tammy. "We went through this alone and we just want to spread the word that something is being done. You are not alone."